

THE FIRST ESTATES GENERAL OF HEPATITIS B:

The civil society is mobilizing
to overcome hepatitis B once
and for all

1. WHY THE ESTATES GENERAL OF HEPATITIS B?
2. HEPATITIS B IN FRANCE AND AROUND THE WORLD
3. HEPATITIS B THROUGH THE EYES OF PATIENTS:
TEN LESSONS TO REMEMBER
4. PROPOSALS FROM THE ESTATES GENERAL OF HEPATITIS B

THE ESSENTIAL

1. WHY THE ESTATES GENERAL OF HEPATITIS B?

The hepatitis B virus is responsible for 900,000 deaths per year around the world, particularly widespread in certain Asian, sub-Saharan African or Latin American countries. Although it is less common in France, it nevertheless kills 1,300 people each year and permanently affects the quality of life for tens of thousands of others. However, there is a highly effective vaccine and, if the person has not been protected in time, there are treatments for chronic infections that help control the disease, if necessary.

Hepatitis B is a deadly yet avoidable disease; a disease against which it is possible to act effectively, but one that we never really talk about...It is in the face of this paradoxical situation, which made participants from the Estates General of Hepatitis B, organized by the SOS Hépatites Federation, want to react.

The Estates General of Hepatitis B decided upon the following objectives:

- better highlight the consequences of hepatitis B in France and raise awareness with both public opinion and health authorities regarding the difficulties encountered by people living with hepatitis B;
- propose improvements to the existing systems and formulate suggestions for a more volunteer based public health strategy against hepatitis B.

More than a year of work, 500 people involved

Organized with the help of the agency Empatient ,<http://www.empatient.fr/empatient/>, the Estates General of Hepatitis B was officially launched in July 2019.

- A steering committee was designated, including fifty or so experts from patient organizations, the medical-social world, research, and medical institutions. The complete list can be referenced here, <https://soshepatites.org/etats-generaux-de-lhepatite-b-les-dates-cles/>
- Patients' stories were heard with three citizen panels organized in Marseille, Paris and Guadeloupe as well as via the survey, "Living With Hepatitis B", conducted by the various partners with people affected by hepatitis B.
- Topic-based roundtables were organized in parallel in Prades, Bordeaux, Strasbourg, Lyon, Rennes and Guadeloupe to help unearth proposals from different medical and social stakeholders.
- Lastly, observations were analyzed, and proposals were drawn up before submitting a summary document, <https://soshepatites.org/wp-content/uploads/2021/02/21-02-16-Premiers-Etats-Generaux-Hepatite-B-SYNTHESE-67p.pdf>, to the government and health authorities in December 2020.

In total, nearly 500 people were mobilized over the course of one year! The Estates General of hepatitis B represents an unprecedented enterprise for health-related democracy, initiated by patients fully justifying their designation in French as "hépatants", which means patients with liver disease but also amazing (in French "épatants") patients.

2. HEPATITIS B IN FRANCE AND AROUND THE WORLD

The Estates General made it possible to share the most recent information on hepatitis B. This event gave stakeholders from medical-social structures the opportunity to better understand the question of medical checkups or treatments, helped the nursing staff take a closer interest in the problems related to accessing treatment for migrants and assisted everybody in better listening to what patients had to say.

This information is summarized in the summary document from the Estates General. Below, are the main points.

A WORLDWIDE PLAGUE

The hepatitis B virus is a very infectious virus, which is transmitted either at birth, from mother to child, or during one's life through contact with blood or biological secretions. hepatitis B is a sexually transmittable disease.

- In France, estimations report that 135,000 people from the general population have a chronic form of the hepatitis B virus for the rest of their lives. Among them, 27,000 have received from the status of long-term illness patients', a classification provided by the Health Insurance office in virtue of chronic hepatitis B.
- Around the world, more than 250 million people have a chronic version of the virus. Approximately 80% of these people do not have access to screening or treatments . With nearly 900,000 deaths, from liver cirrhosis or cancer, hepatitis B is the deadliest of the viral hepatitis diseases.

THE VACCINATION IS MAKING HEADWAY

- Since 2018 in France, the hepatitis B vaccine is one of 11 mandatory vaccines for newborns. Thanks to this initiative, vaccination coverage has been considerably reinforced and, by the age of 2, more than 9 out of 10 children have been protected against hepatitis B.
- However, anti-HVB vaccination coverage in adolescents remains rather insufficient, as less than half of them are actually vaccinated; despite the "catch-ups" currently recommended for unvaccinated children and adolescents until the age of 16.
- The vaccine is refunded at 70%, but is free in free health dispensaries and vaccination centers.
- At the worldwide level, the vaccination has recorded spectacular progress over the course of the past 20 years. In 2000, only 30% of young children had received 3 doses of the hepatitis B vaccine; in 2019, the number had risen to 85%. However, access to the vaccine's first dose as of birth remains irregular despite its major importance. On average, worldwide coverage of this dose at birth is 43%, but only 6% in the African region .
- Today, less than 1% of children under the age of 5 around the world present a chronic HBV infection, compared to 5% before 2000. This represents a giant step towards the elimination of hepatitis B.

SCREENING REMAINS IMPERATIVE

The vaccination's progress provides great hope. However, it is not sufficient. To overcome Hepatitis B once and for all, we need to screen everyone who has not been vaccinated to prevent the illness and its complications as well as protect patient's close contacts from an eventual contamination.

- Each year, approximately 4.3 million screening tests for the hepatitis B virus (HBV) are carried out in France. This hepatitis B screening is mandatory when giving blood and for pregnant women.
- Screening tests are not fully refundable. However, they are free in anonymous and free screening information centres (in French CeGIDD).

- **Rapid diagnostic tests (in French Trod)**, are carried out with a blood sample taken from the fingertip, this form of testing is less precise than classic blood samples. However, they represent an additional method for reaching groups of people particularly exposed and less likely to have access to healthcare structures. Unfortunately, the conditions for carrying out and financing these tests, nevertheless recommended by the French National Health Authority, was not yet published by the end of 2020.

TREATMENTS TO CONTROL THE DISEASE

People living with chronic hepatitis B virus do not all need to be treated. An initial, a detailed report is necessary to define the stage of the disease, which passes through different phases of wide-ranging characteristics and severity. Medication is available, the choice of medication depends on the patient and the virus's characteristics.

In 2020, antiviral treatment was recommended for chronically infected patients having cirrhosis or presenting a risk of developing cirrhosis or cancer, immuno-depressed patients (for example: co-infection with HIV, taking immunosuppressant medication, etc.), as well as for pregnant women presenting a significant viral load. The treatment's main objective is to avoid the formation of cirrhosis and its complications by controlling its viral replication. It is considered to be effective when hepatitis B DNA is no longer detectable in the blood.

Medical fees are fully refundable as soon as a patient has one of these therapeutic indications; this allows for the full reimbursement of the treatment, hepatitis monitoring, and its efficacy and tolerance.

NUMEROUS STAKEHOLDERS INVOLVED

The Estates General reminded everyone: patients are, of course, the main actor in their own health. In the case of chronic hepatitis B, they must receive support from numerous medical, paramedical and medical-social stakeholders, as well as their peers, through user organizations. The list of participants at the Estates General alone shows the variety of contributors!

- **A general physician**, hepatic gastroenterologist, infectious disease specialist or internist, represent the ideal team. Numerous other medical figures are also solicited: radiologists, biologists, Ob-Gyns, pharmacists, as well as addiction specialists, psychiatrists, nephrologists, etc.
- **Paramedical and medical-social figures** also participate: nurses, psychologists, dieticians, social workers, social assistants, etc.
- **Different care devices** make it possible to coordinate this multidisciplinary assistance: healthcare networks, addiction centers, medical microstructures, etc. Expert services in the fight against viral hepatitis (in French SELHV) are specialized in complicated forms of the disease as well in training healthcare professionals.
- **Structures treating and helping vulnerable populations** such as Médecins du Monde, which treats, acts in favor of and assists the most vulnerable of populations, and the Comede, which works in favor of the health of those in exile and defending their rights.
- **User organizations** (SOS hépatites, AIDES, Transhépate, ASUD, TRT-5 CHV) mainly participate in providing information to the general public, listening, assisting and supporting patients and their family, by prioritizing the sharing of experiences between peers.

QUALITY OF LIFE, AN ESSENTIAL OBJECTIVE

To understand what quality of life means, we could compare it to a 5-pointed star, with each point indicating a different kind of health: physical, social, sexual, psychological and emotional. Like with other chronic diseases, we need to take account of hepatitis B's impact on the 5 points of this star.

- **Each stage in life needs its own information and assistance.** Experience proves it: in terms of chronic disease, access to clear information is not sufficient. A person's life with its unique educational, environmental, familial, social, sexual or professional factors must be taken into account to provide

adapted information, provided progressively at the right time: during the hepatitis B diagnosis, at the stage of chronic hepatitis, at the stage of cirrhosis, when trying to become pregnant, on the occasion of a romantic encounter, etc.

- **Treatment-based education** has a major role in helping patients better understand the illness and its transmission risks. For patients, the reality is not just about signing up for a treatment program. They must learn to live with the disease and incorporate it into their daily life . They must have reliable, understandable, and update information.
- **At the professional level, hepatitis B must no longer be an obstacle** when exercising one's profession, including in the medical sector. The Higher Council for Public Health clearly confirmed this in 2014 : with treatments able to control hepatitis B, there is no longer any justification regarding the need to impose restrictions on activity, regardless of what it is, subject to the fact that precautions related to hygienic standards are followed and the viral load is regularly checked to make sure that it remains undetectable.
- **Access to care for people born abroad** is a major preoccupation with hepatitis B, quite frequent in their country of origin for many migrants from Africa or Asia, specifically. Since 2016, the attribution and renewal of temporary residency cards for ill foreigners have decreased, following a reform on admission procedures. For foreigners without papers, State Medical Aid (in French AME) helps people access treatment, but it too has seen its attribution conditions become stricter, at the risk of leaving people afflicted with hepatitis B without support or treatment.

THE HEPATITIS DELTA VIRUS WAITING IN AMBUSH

Hepatitis D, or the hepatitis delta virus, is known as a "defective" virus because its multiplication requires the presence of the hepatitis B virus. Approximately 5% of patients with chronic hepatitis B are also infected with hepatitis D. They suffer from more severe hepatitis, with earlier and more frequent signs of cirrhosis and cancer.

For a long time, treatment methods were limited to interferon, which was not very effective. Since then, Bulevirtide can also be used, which opens up new treatment perspectives. However, it should be reminded that the best treatment for hepatitis D, in terms of efficacy and tolerance, remains the hepatitis B vaccine: if a person does not have hepatitis B, they cannot get hepatitis D!

The survey "Living with hepatitis B" carried out under the framework of the Estates General (see hereafter) shows a real deficit in information regarding this virus: 4% of people with hepatitis B responded saying they know they have hepatitis D, but 44% do not know their status regarding the delta virus. Today, stakeholders need to mobilize to avoid the "double penalty" that this secondary delta infection represents.

3. HEPATITIS B THROUGH THE EYES OF PATIENTS: TEN LESSONS TO REMEMBER

A major objective from the Estates General was to better understand the “experience” of hepatitis B by those who have it, including both their perception of the illness and their expectations. A questionnaire was created, including fifty or so questions. Nearly 200 people responded. The detailed results are accessible in the Estates General summary document (page 35), <https://soshepatites.org/wp-content/uploads/2021/02/21-02-16-Premiers-Etats-Generaux-Hepatite-B-SYNTHESE-67p.pdf>. Here, we have selected 10 main lessons that we should keep in mind.

- 1 If persons haven't been screened, they don't feel concerned.** 81% of people asked did not feel concerned about hepatitis B before their positive diagnosis. This is the first lesson to learn from this study: hepatitis B affects others...until one is diagnosed with it.
- 2 Once screened, the illness creates strong fears, both for one's self as well as for others.** When they are asked what is the most difficult thing to live with, among the repercussions of hepatitis B, 59% of people cited the uncertainty regarding the illness's evolution, while 57% answered the fear of cancer. Right behind that was the fear of contaminating other people at 56%.
- 3 The impact of hepatitis B on one's personal life is very real.** This is another major lesson from the survey: for 50% of people, hepatitis B has an impact on morale (25% in a significant way, 25% only moderately). And for 42%, it has an impact on one's own self-image. Also cited, was the impact on professional life, cited by 31% of people, the impact on family life (30%), sexual life (29%) and the life of the couple (26%).
- 4 One out of two people with hepatitis B can count on the support of their partner.** Faced with these difficulties, who can a person count on? The first line of support is one's partner, cited by 46%, then their physician (33%), their family or friends. People also cited a multitude of precious contributors and support structures (social services, pharmacists, charity organizations, risk-reduction organizations, etc.). However, 23% of people have no one who helps or supports them on a daily basis.
- 5 Physicians provide the first-line of information.** 76% of people with hepatitis B say that they received information regarding the illness in a medical consultation, while 38% did their own research. Thanks to this, they consider themselves able in the most part (79%) to follow the progress of their disease.
- 6 Transmission methods are more or less well known.** Overall, people with hepatitis B know the three main transmission methods for the virus: unprotected sex (89% cite this transmission method), transmission through the exchange of blood between two people (88%) and mother-to-child transmission, during birth (78%).
- 7 Talking about the disease with one's friends and family is not always easy.** 74% of people questioned have spoken about hepatitis B and its prevention with their friends and families. They first did so “to be honest” (reason cited by 73% of people concerned), then “to encourage them to get tested” (55%) and/or “to encourage them to get vaccinated” (50%). When they could not speak about it to their entourage, it was mainly “due to fear of being rejected” (70%).

8 Trust in the vaccine is not absolute, even in people with hepatitis B. The most effective prevention against hepatitis B is the vaccine. A sign of the times, defiance against this vaccine has even infiltrated people with hepatitis B: 24% of people said "that they did not trust it" and 7% preferred not to say.

9 Long-term monitoring sometimes lacks continuity. After a positive screening, 85% of people confirmed taking a liver exam (blood test, CT, liver biopsy, etc.). However, chronic hepatitis B also calls for long-term monitoring to keep a close eye on the evolution of the fibrosis and potential cirrhosis. In our sample (albeit most likely better monitored than the average patient in France), only 65% of people have an ultrasound done at least once a year, and 9% at a less-frequent rate. That is insufficient!

10 The need for information remains important. When users are questioned about their needs to better manage their hepatitis B and improve their daily lives, two requests both stand out almost equally: be better informed regarding the illness in general (67%), as well as "be better informed on what we can eat and drink" (68%).

4. PROPOSALS FROM THE ESTATES GENERAL OF HEPATITIS B

At the end of this long journey, which was supposed to make new ideas come to the forefront, the Estates General's steering committee formulated approximately forty concrete proposals for a policy in the fight against hepatitis B that is both more effective and attentive to patients' needs. These proposals, regrouped as 6 priority initiatives, are downloadable in their entirety here (page 50), <https://soshepatites.org/wp-content/uploads/2021/02/21-02-16-Premiers-Etats-Generaux-Hepatite-B-SYNTHESE-67p.pdf>. They represent what could, in our eyes, represent a genuine strategic program against hepatitis B, both ambitious and realistic. Together, patients and medical/social stakeholders will be able to win this fight against hepatitis B!

PRIORITY FOCUS 1:

IMPROVE OPINIONS REGARDING HEPATITIS B

Not very well known, hepatitis B remains the victim of numerous prejudices, which is at the root of the disease's stigmatization. We need to change its image through positive, simple and clear communication. To do this, the Estates General recommends:

- Initiating both "general public" and "community-based" de-stigmatizing informational and awareness-raising campaigns on hepatitis B and hepatitis D, screenings, vaccinations, lifelong medical checkups, the refusal to remain isolated.
- Increase the training of in-the-field stakeholders (general physicians, nurses, psychologists, social assistants, community-based associations, etc.) and circulate concrete, simple and innovative informational tools on hepatitis B and hepatitis D to all stakeholders, co-created with those who are affected by the disease (protect their close contacts, carry out medical checkups, have children, etc.).

PRIORITY FOCUS 2

BETTER UNDERSTAND THE EPIDEMIOLOGICAL REALITIES OF HEPATITIS B

Hepatitis B is a silent and under-screened disease, and thus insufficiently documented from an epidemiological point of view. To better act against hepatitis B and hepatitis D, we need to better understand what they affect and how:

- By carrying out general and more specific epidemiological studies in all regions, including overseas departments, regarding the vaccination rate of a person's close contacts, with communities specifically concerned (migrants, unaccompanied minors, etc.)
- By conducting sociological studies on understanding, representation, repercussions and specificities with infected populations.

PRIORITY FOCUS 3

SUPPORT AND ENSURE LEARNING FOR PEOPLE WITH HEPATITIS B

A complicated and changing disease, hepatitis B requires a genuine "apprenticeship," to better understand its issues, support its uncertainties, adhere to regular and lifelong checkups and eventual treatment.

- This will occur, for example, through an ambitious treatment-based education policy for patients, which will be the subject of several proposals: by generalizing its access to all patients concerned and launching regional calls for projects.
- Learning also occurs through peers, which means supporting concerned organizations, developing peer exchange groups on social media, developing easy-to-understand self-help information, co-created with concerned communities and translated into different languages.
- Health-based mediation, the management of one's psychological wellbeing, as well as sexual health, must also be much more widely developed;

PRIORITY FOCUS 4

IMPROVE THE CARE AND TREATMENT OF THOSE WITH HEPATITIS B

Just like for hepatitis C and HIV/AIDS, screening everyone at least once in a person's life should be put into practice. However, it is not enough just to facilitate the diagnostic, we also need to encourage regular and lifelong monitoring and reassure about the need for treatment or not. This topic is the subject of approximately a dozen proposals from the Estates General, among which:

- Completely reimburse, as of the diagnostic and for the rest of a person's life, non-invasive tests and exams to evaluate the fibrosis and set up an annual checkup regarding liver health for all people with hepatitis B or D.
- Facilitate overall coordination between the different stages of the process, by developing systematic, post-diagnostic treatment networks combining hospitals, general physicians, gynecologists, medical-social structures, patient associations and organization working with affected populations.
- Reach the objective "Zero contamination for children born in France" with optimized screening at the beginning of pregnancy, communicating medical files with midwives and making rapid diagnostic tests available in delivery rooms.
- Remove the numerous obstacles limiting access to screenings and care for migrants, whether they have papers or not, and better protect unaccompanied minors.

PRIORITY FOCUS 5

STRENGTHEN PREVENTATIVE MEDICINE BY COMBINING SCREENINGS AND VACCINATIONS

Prevention is the foundation in the fight against hepatitis B: disease prevention through vaccination, prevention of complications through screenings and lifelong monitoring for those with chronic versions of the disease. Faced with such stakes, the entire medical-social chain must be mobilized.

The Estates General specifically proposed:

- Developing and increasing the means for preventative medicine, Centers for information and screenings, continuous access to healthcare and organizations in order to carry out initiatives combining screenings, vaccinations and overall health with the most affected populations.
- Educating concerned stakeholders so that they can carry out more hepatitis B rapid diagnostic tests.
- Mobilizing laboratories, both to encourage screenings as well as give them the green light to research certain hepatitis B markers, including hepatitis D and fibrosis.
- Launching a positive campaign on the hepatitis B vaccination by providing "I am vaccinated against hepatitis B" badges to healthcare professionals.

PRIORITY FOCUS 6

STRENGTHEN NORTH-SOUTH COLLABORATION

Consistent with the objectives defined by the World Health Organization to eliminate hepatitis B between now and 2030, it is at the global level that the strategy against this virus must be designed.

The Estates General specifically recommended:

- Prioritizing, around the world, screening and vaccination initiatives for women, screenings for pregnant women and the vaccination of newborns.
- Acknowledging each person's right to access screenings and vaccinations. Throughout the world, people with hepatitis B must be supported so that they can always remain involved in their own health, with or without treatment, whether they are migrants or have just returned to their country of origin.
- Including hepatitis, with additional dedicated resources, among the pathologies in the Global Fund to fight AIDS, tuberculosis and malaria to ensure access to vaccinations and treatment in all countries.
- In France, focus on child protection for unaccompanied minors, the right to information and healthcare and, specifically, provide them with an education in overall and sexual health.

1 World Health Organization (WHO). Hepatitis B, published on July 5, 2019. <https://www.who.int/news-room/fact-sheets/detail/hepatitis-b>

2. World Health Organization (WHO). International hepatitis B Awareness Day: accelerate the elimination of hepatitis B in mothers and children, July 27, 2020. <https://www.who.int/news-room/detail/27-07-2020-world-hepatitis-day-fast-tracking-the-elimination-of-hepatitis-b-among-mothers-and-children>

3. Collectif (Im)patients Chroniques & Associés, Parcours de santé des personnes malades chroniques. <https://www.endofrance.org/ledition-2019-du-guide-parcours-de-sante-des-personnes-malades-chroniques-enfin-disponible/>

4. The HCSP's recommendations related to the course of action to take for people with chronic hepatitis B who would like to integrate training programs listed in the decree from March 6, 2007, December 16 and 18, 2014, Version from April 21, 2015. <https://www.hcsp.fr/explore.cgi/avisrapportsdomaine?clefr=514>

The Estates General of Hepatitis B was able to take place through the mobilization of all participating structures as well as the following support:

- **Institutional support:** ISM Interprétariat.
- **Institutional and financial support:** ANRS, ARS Auvergne-Rhône-Alpes, ARS Bretagne, ARS Guadeloupe, Conseil régional d'Ille-et-Vilaine, DGS, SOS hépatites.

PRESS CONTACTS

Pascal Mélin, President of the SOS hépatites Fédération, +33 7 85 62 91 69

Carmen Hadey, SOS hépatites referent on "hepatitis B and vaccinations," +33 7 83 71 57 68

Selly Sickout, Director of the SOS hépatites Fédération, +33 6 74 86 44 48

Follow us:

Facebook : <https://www.facebook.com/SOS.hepatites.Federation/>

Twitter : [@SOS_hepatites](https://twitter.com/SOS_hepatites) / Twitter

Instagram : [@soshepatites](https://www.instagram.com/soshepatites) • Photos et vidéos Instagram

Site internet SOS hépatites : <https://soshepatites.org/>

► N°Vert 0 800 004 372

Signatories of the summary report from the First Estates General of Hepatitis B

